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The European Code of Cancer Practice

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ABSTRACT

There are considerable disparities between the quality of cancer care and clinical outcomes for cancer patients in different European countries, regions, hospitals and communities. These have persisted despite the introduction of many European and National Cancer Plans, an extensive portfolio of clinical guidelines and the existence of evidence based guidelines for the good practice in planning cancer healthcare systems. We describe the European Code of Cancer Practice which is a citizen and patient-centred accessible widely disseminated statement of the core requirements for good clinical cancer practice. The Code sets out 10 key overarching Rights of what a patient should expect from their healthcare system each supported by a plain language explanation. The Rights highlight the importance of equal access to affordable and optimal cancer care, good quality information about an individual patient's disease and treatment and about the quality and outcomes of the cancer service they will use. Specialised multidisciplinary cancer care teams, shared decision-making, research and innovation, a focus on quality of life, the integration of supportive and palliative care within oncology are all emphasised. There is a need for a systematic approach to supporting cancer survivors with a survivorship care plan including their rehabilitation, reintegration into society and return to work where appropriate without discrimination.

The Code has been co-produced by a team of cancer patients, patient advocates and cancer professionals to bridge the gap between clinical guidelines, healthcare policies and patients' everyday experience. It is robustly evidence-based and supported by a comprehensive review of the medical literature and evidence for good clinical

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practice. The Code is strongly endorsed by Europe's professional and patient cancer organisations and the European Commission.

1. Background

New knowledge of biology, detection, treatment and patient care has resulted in radical improvements in outcomes for many patients with cancer, alongside an enhanced patient experience and better quality-of-life (QoL). Over half of all patients with cancer who receive state-of-the-art diagnosis and treatment can expect long-term survival and good QoL beyond 10 years after their diagnosis; for most of these people, the outcome is a cure of their disease. However, for certain cancers, notably brain tumours, oesophageal, pancreatic, liver and lung cancers, progress remains limited and prognoses are generally poor. Cancer and the provision of cancer care still places a significant burden on Europe's patients, citizens and economies. As the European population ages and if lifestyle-associated cancer risks (eg smoking, obesity) are not adequately addressed, then in many European countries more than half of the population will develop a cancer at some time during their lives

Fig. 1. The European Code of Cancer Practice.

1) You have a right to equal access to affordable and optimal available cancer care, including the right to a second opinion.

Three key questions that every cancer patient may choose to ask:

1. *Will my care be the best available and comparable to other high quality cancer care and good clinical cancer practice in my country and elsewhere in Europe?*
2. *Are patient outcomes in our cancer care service as good in general as in other centres in my country and elsewhere in Europe?*
3. *Do I have the right to ask for a second opinion if I so wish?*

2) You have a right to information about your own disease and treatment from your medical team and other reliable sources, including patient and professional organisations.

Three key questions that every cancer patient may choose to ask:

1. *Will I be able to decide how much information I should receive about my diagnosis, treatment (including the benefits and risks) and the management of my disease?*
2. *May I bring a relative or friend to my consultations?*
3. *Will I receive written information about my cancer and will I be given contact details for relevant patient organisations?*

3) You have a right to information about the quality and safety of care, the level of expertise and the outcomes achieved for your type of cancer in the cancer care service where you are being treated.

Three key questions that every cancer patient may choose to ask:

1. *Will my diagnosis and treatment be managed by a team of healthcare professionals with the necessary expertise to give the best advice and identify the best available options for me?*
2. *Is that team specialised in the particular cancer with which I have been diagnosed?*
3. *Does my healthcare team keep records of their clinical outcomes which I may see in an anonymised format, and will I be able to compare those outcomes to those achieved by similar teams in similar institutions?*

4) You have a right to receive care from a specialised multidisciplinary team, ideally as part of a cancer care network.

Three key questions that every cancer patient may choose to ask:

1. *Is my care discussed by a multidisciplinary team?*
2. *Are my views and preferences clearly communicated to this team in a timely fashion?*
3. *Is our cancer service part of a cancer network?*

5) You have a right to participate in Shared Decision-Making with your healthcare team about all aspects of your treatment and care.

Three key questions that every cancer patient may choose to ask:

1. *May I discuss the approach that we will take in making decisions about my care and agree how my voice is heard?*
2. *May we share decision-making so I feel empowered to decide on my care options?*
3. *Does our cancer service encourage patient engagement, involvement and empowerment?*

6) You have a right to be informed about ongoing research relevant to you, and your ability and eligibility to participate in research.

Three key questions that every cancer patient may choose to ask:

1. *Is our cancer service active in performing cancer research, enrolling patients in clinical trials and supporting innovation?*
2. *Is there a study or clinical trial in which I could participate if I am eligible and if I choose to do so?*
3. *May I go to another hospital or centre if I wish to be involved in a specific clinical research project not offered at my hospital or centre?*

7) You have a right to discuss with your healthcare team your priorities and preferences to achieve the best possible quality-of-life.

Three key questions that every cancer patient may choose to ask:

1. *During and after my treatment, how will I be able to maintain the optimum quality-of-life so that I can live as normally as possible?*
2. *Does our cancer service measure the quality-of-life of patients in any way, such as using Patient Reported Outcome Measures (PROMs)?*
3. *Does our cancer service actively consider whether people have emotional, social or financial problems pertaining to their diagnosis or treatment?*

8) You have a right to receive optimal supportive and palliative care, as relevant, during any part of your cancer journey.

Three key questions that every cancer patient may choose to ask:

1. *Will I be given supportive and palliative care on my cancer journey, based on my individual needs?*
2. *Can I ask to be referred to the supportive and palliative care service at any time?*
3. *Is the supportive and palliative care service provided at home and in hospital?*

9) You have a right to receive and discuss with your care team a clear, managed and achievable plan for your survivorship and rehabilitation.

Three key questions that every cancer patient may choose to ask:

1. *Will our cancer service help me face my challenges as a cancer survivor?*
2. *Will I be given a **survivorship care plan** to help me cope with any problems I may encounter as a cancer survivor?*
3. *How do I access supportive and rehabilitation help for cancer survivors?*

10) You have a right to be fully reintegrated into society and protected from cancer-related stigma and discrimination, so that, in so far as is possible, you can return to work and a normal life.

Three key questions that every cancer patient may choose to ask:

1. *Should I anticipate any difficulties in fully reintegrating into society, including within my family and in social and work environments?*
2. *If I do experience problems in any of these areas, to whom can I turn for help and advice?*
3. *Where can I obtain advice on the legal issues that may relate to my employment, financial issues such as insurance and family issues such as international travel and holidays?*

Fig. 2. Questions that patients may ask in their consultations about the 10 Rights in the European Code of Cancer Practice (from Reference [1].

[1–23].

The European Code of Cancer Practice ("The Code") [1], (Fig. 1) is a citizen and patient-centred accessible, widely disseminated statement of the core requirements for good clinical cancer practice. The Code sets out a series of 10 key overarching rights, signposting what all patients (paediatric, adolescent and adult) should expect from their health system at all stages of their cancer journey, in order for them to achieve the best possible outcomes. It has its origins in the European Cancer Patient Bill of Rights [2–4]. It is an empowerment tool and a resource to ensure the best available care is delivered for European citizens and patients. The Code has been systematically co-produced by a team of cancer patients, cancer professionals and patient advocates to "bridge the gap" between policy, clinical guidelines and the everyday experience of patients and carers.

Each of the 10 overarching rights is linked to three questions that a patient (or for paediatric patients their parent/guardian) may choose to ask their healthcare professionals (Fig. 2). Each right is supported by a short Explanation (Appendix A) and by a review indicating the best available medical literature, evidence-based guidelines and research evidence upon which the recommendations of the Code are based [1]. These include the Essential Requirements for Quality Cancer Care (ERQCC) series developed by the European Cancer Organisation(ECO) [24–31]. The whole programme of advocacy and guidance tools is designed to be of value for people with cancer, people at risk of cancer, carers, parents/guardians, patient advocates, educators and healthcare professionals and their trainees and may be found on the ECO website [1]. Timely diagnosis and treatment, good primary care and diagnostic capacity are vital; cancer prevention and screening are excellent ways to reduce deaths from certain cancer types [21–33].

This paper describes the Code, the scale of the challenge, the vision of what may be achieved and the meaning of good practice in clinical cancer care, coupled with the next steps for implementation and evaluation. The partnership between patients, advocates and professionals is essential. Research and innovation have a key role.

1.1. The challenges and disparities faced by European cancer patients and health systems

The increasing complexity of cancer diagnostics and treatment, the spiraling costs of healthcare and the ageing population all create significant pressures on healthcare services; these challenges are met unequally across Europe [2–23]. Future healthcare may become confusing and unsatisfactory to patients and costs may make it difficult to provide sufficient time for the skilled health professionals required to engage with patients. Therefore, alongside the provision of excellent professional cancer care, empowered and informed patients can make a substantial contribution to ensure good practice and quality assurance.

While Europe delivers high-quality cancer care and globally-

Table 1
Avoidable deaths in 2010 in EU: two different survival improvement scenarios (adapted from reference [44]).

STOMACH CANCER	COLORECTAL CANCER	LUNG CANCER	BREAST CANCER	ALL CANCERS
Avoidable deaths when country-specific survival is raised to the top quartile of the EU				
3426	13,659	5206	9620	108,372
Avoidable deaths when country-specific survival is raised to the median of the EU				
1321	6815	2476	5926	50,607

The top panel shows the impact on cancer survival in the EU of raising the outcomes of all cancer patients to match those that are already achieved in the top 25 % of countries, which are making use of most of the known good cancer practices. In the lower panel, the impact is shown of raising the survival of all European patients up to the median average for EU countries - perhaps a more readily achievable goal. The study indicated that 50,000–100,000 additional people each year could survive their cancer diagnosis, if good practices were comprehensively implemented across EU countries [44].

recognised cancer research, there are significant disparities within and between European nations, regions, hospitals and communities. There are disparities in: accessing information; accessing optimal treatment with all treatment modalities and optimal outcomes; being treated by networked, multidisciplinary cancer care teams; ensuring good communications and appropriate shared decision-making; integrating cancer research and innovative cancer care; ensuring the best QoL for patients on treatment and thereafter; integrating palliative care and supporting cancer survivors [2–23,34–40]. Disparities between the quality and outcomes of cancer care between countries, regions, hospitals and communities may reflect variation in the provision and uptake of good clinical cancer practice, but may also be influenced by socio-economic, cultural and geographical factors [10,17,41–43]. Table 1 shows the potential impact of implementing existing good practices in cancer on European and national outcomes [44]. Improvements in the quality of care, translation of research discoveries, and promotion of innovation will have to be achieved within affordable and efficient healthcare models [2–16,45].

1.2. The 70:35 vision

In countries with good clinical practice and organisation, on average long-term cancer survival is experienced by 60 % of patients, although there may be significant variation between regions, hospitals and communities due in part to differences in diagnosis, including screening, and treatment. However, concerted and consistent action is needed to bring all of Europe's cancer care up to an acceptable level and this will involve informing and empowering patients, providing and training professional staff in adequate numbers, establishing and sustaining their expertise, providing facilities, equipment, material including medications, information systems, and excellent management and leadership [1–4].

Our aim is to reach 70 % survival on average beyond 10 years for all European citizens by 2035, improving both the length and the quality of cancer patients' survival [4].

This "70:35 Vision" should be addressed by two processes simultaneously:

1 **Identifying, sharing and implementing good practice in cancer diagnosis and care** through an actively managed, systematic approach across countries, regions, hospitals and communities. We envisage that this process by itself would raise long term patient survival from an average of ~50 % to ~60 %.
2 **More intense research and innovation in discovery, translational, clinical and health-related cancer sciences** has the real potential for a further increment in long-term survival towards 70 %, whilst improving both quality of life and the patient experience.

We need credible tools to help patients benefit from their healthcare system, promote good practice and a patient-centred approach. The Code is such a tool.

Cancer care planning must consider trends in incidence and mortality. The Swedish Institute for Health Economics [6] has comprehensively described the epidemiological context for good cancer control. In 1995, the estimated number of cancer patients diagnosed in Europe was 2.055 million; by 2018 it had increased to 3.081 million. Even correcting for the impact of the ageing population, in men, incidence rates for cancer have increased in the majority of countries; however, Iceland, Austria, Finland, Poland, Switzerland, Italy and Czechia have recorded slight decreases in men. In women, incidence rates have increased in all countries except Iceland [6]. Cancer deaths have also increased, from 1.191 million in 1995 to 1.445 million in 2018, reflecting rising cancer incidence and the ageing population. Increasing age results in a higher incidence of cancer and poorer survival. However, age-standardised cancer mortality rates have fallen in men and in women in most European countries; ~5 million cancer deaths have been avoided in the European Union (EU) over the last three decades [6,46]. People up to the age of 64 years are showing improvements in cancer mortality. The influence of age on survival is likely to reflect patient fitness, patient and professional attitudes and healthcare access and is important in planning healthcare [6,47–49].

Table 2
Key features of international and national specifications and guidelines for Good Clinical Cancer Practice [1].

1. Patient-centred, specialised, and integrated multidisciplinary care for the timely delivery of the appropriate modalities of treatment (often combined), and supportive care:
   - o Surgery [Right 1]
   - o Radiotherapy [Right 1]
   - o Chemotherapy [Right 1]
   - o Biological and immunological therapy [Rights1 and 6]
   - o Psychosocial care [Rights 5 and 7]
   - o Palliative care at all stages [Right 8]
2. Prompt delivery of treatment as soon after diagnosis as possible
3. A wide range of professional groups in the planning and delivery of cancer care (Right 4)
4. Attention to all age groups, including those with age-specific requirements including children, adolescents and young adults, and older cancer patients [Right 1]
5. A focus on patient centred outcomes including Quality of Life using Patient Reported Outcome measures [Right7]
6. Good communication between patients and healthcare professionals about the patient's diagnosis and treatment and the quality and outcomes of the care in a cancer service [Rights 2, 3 and 5]
7. Well organised care integrated across a region as a network to deliver care as near to a patient's home as is safe and feasible, supported by good information systems [Right4]
8. Research and innovation as a core part of the work of the cancer care team [Right 6]
9. Survivorship planning, rehabilitation and support for reintegration into family, social and working lives [Rights9 and 10]
10. An active programme of oncology education [Rights 1−10]

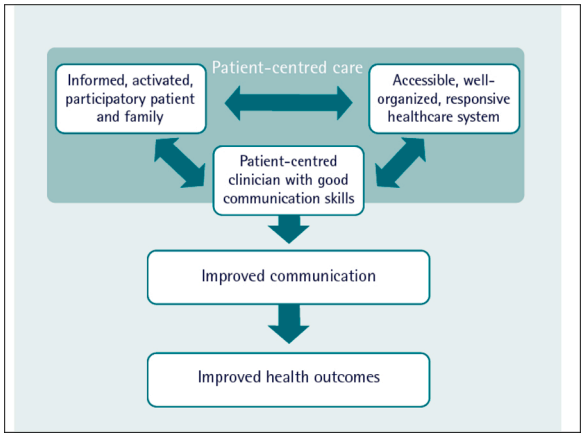

Fig. 3. Patient-centred cancer care. "The development of cancer services should be patient-centred and should take account of patients, families and carers' views and preferences as well as those professionals involved in cancer care. Individual's perceptions of their needs may differ from those of the professional" [71]. Good communication between professionals and patients is especially important. Fig. 3 is adapted from Abrahams et al [70].

1.3. What is good clinical cancer practice?

Good practice in the timely delivery of clinical cancer care is defined by service specifications and guidelines from international and national governmental and non-governmental organisations (Table 2). The ERQCC currently includes breast, prostate, oesophageal/gastric, lung and colorectal cancers, melanoma and sarcoma and primary care; work is in progress for pancreatic, ovarian cancer and glioma [24–31]. The European Society for Medical Oncology (ESMO) has a standard methodology for producing its comprehensive portfolio of topic- and

Table 3
Research and Innovation which is improving cancer practice (from references [92–104].

1. Advances in understanding the cell and molecular biology of cancer and cancer genetics which characterise the hallmarks of cancer, underpin advances in cancer pharmacology and drug development, immunology and microbiology, immunotherapy and vaccines [92,93,94].
2. Precision oncology allows clinicians and patients to choose the right treatment at the right time [95].
3. New radiotherapy technologies allow ever more targeted treatment approaches [97, 98,99,100].
4. Surgical advances include robotics, minimally invasive technologies, imaging enabled approaches, and oncoplastic reconstructive surgery [34,55].
5. Interventional radiology/oncology are providing means of destroying localised cancers using heat or cold [101].
6. Physical Sciences are delivering new tools to improve diagnostics and all treatment modalities [102].
7. Health Informatics and Artificial Intelligence/Machine Learning can inform service planning and delivery [13].
8. Applied health research provides insights into the effective organisation of healthcare [6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23].

disease-specific clinical guidelines [50]. The European Commission has supported Member State Joint Actions against cancer, the European Partnership for Action Against Cancer (EPAAC) and the Cancer Control Joint Action (CanCon) which have already reported their results, while the Innovative Partnership for Action Against Cancer (iPAAC) is in progress. These initiatives provide frameworks for action to improve cancer outcomes [5,7,8]. European and national cancer societies, leagues and organisations promote good cancer practice individually and as part of collective European anti-cancer efforts [50–69]. We summarise the key features of good clinical cancer practice in Fig. 3 [70,71], Table 2 and in the Code's Rights 1−10 below.

Currently, European countries' cancer care and cancer services are organised in different ways, reflecting history, population, culture, health system structure and resources. In most systems, there is room for improvement, despite the existence of National Cancer Control Plans (NCCPs) in most European countries [17]. Expertise is often centralised into cancer centres which may be a part of a main general hospital or are separate institutions [72–74]. The Organisation of European Cancer Institutes (OECI), in its voluntary accreditation procedure [74], lays emphasis on a wide range of elements, including infrastructure for cancer care, human resources, clinical care activities, research activities, education and institutional structure. The OECI standards, which include academic and research activities and credentials, are an important part of Europe's cancer care activities and frequently provide beacons of excellence, which can inform care in other facilities within different European countries and regions. These standards cover and reinforce all 10 of the overarching rights of the Code, to which accredited cancer centres should comply [74–76].

For good clinical cancer practice, adequate numbers of highly trained professional multidisciplinary teams, appropriate facilities and equipment to provide inpatient and outpatient diagnostics, treatment and follow-up are essential [see Right 1 and 4] [1–31,50–69,72–76]. In order to develop and sustain their expertise, teams and institutions need to perform a substantial volume of work. Delivering complex care - especially for patients with rare or advanced cancers and some complex "high technology "treatments - may require centralisation of services with a specialised team in a limited number of hospitals. However, much cancer care can be delivered close to a patient's home, including some diagnostics, follow-up and relatively straightforward cancer treatments. The literature on the relationship between the volumes of clinical activity (patient or procedure numbers) required to establish and sustain good clinical practice and outcomes is extensive [77–85]. The degree of centralisation varies between different cancers and treatments [24, 2–31] and care close to home, together with assuring equity of access, and consistency of good practice, is facilitated by high-performing cancer care networks [86–91] (ECCP 4).

Good practice requires constant review, updating and continuing education and will evolve substantially over time. Currently, research and innovation, often using established scientific concepts and technologies, are enhancing good clinical cancer practice continuously (Table 3) [92–103]. Collaborative research organisations including the European Organisation for Research and Treatment of Cancer (EORTC, 63), Cancer Core Europe [104] and the European Academy of Cancer Sciences [69] have a key role to achieve the ambitious goals of the Code.

1.4. Patient involvement, engagement and empowerment

Patient involvement, engagement and empowerment can improve patient satisfaction, the quality of care provided, and patient outcomes [105]. 'Engagement' expresses the commitment of healthcare professionals to intentionally and meaningfully include patients in discussions and decisions about their care. 'Empowerment' is a wider concept that encompasses commitment and action by patients who are self-derived and self-driven and may occur outside the interactions with healthcare professionals. The European Patients' Forum (EPF) has developed a Charter on Patient Empowerment [106]. Systematic reviews of scales that measure empowerment exist [107]. The OECI has 38 quality standards on patient involvement and empowerment which accredited cancer centres should comply with, ranging from co-creation of services, to shared decision-making [108]. Patient involvement, engagement and empowerment are ethical imperatives and an evidence-based choice, resulting in better psychosocial and economic

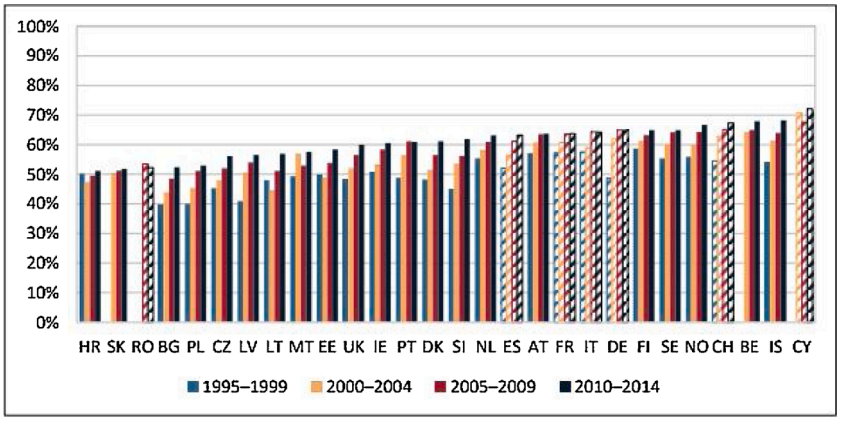

Fig. 4. 5-year age-standardized net survival rates for colon cancer in European adult patients (15-99 years), 1995-2014. Hatched bars are based on regional data or neighbouring countries. Survival ranged from 51 % in Croatia to 68 % in Belgium and Iceland. Over half of European countries are now reporting survivorship at five years at or above 60 % (from reference [6] with permission).

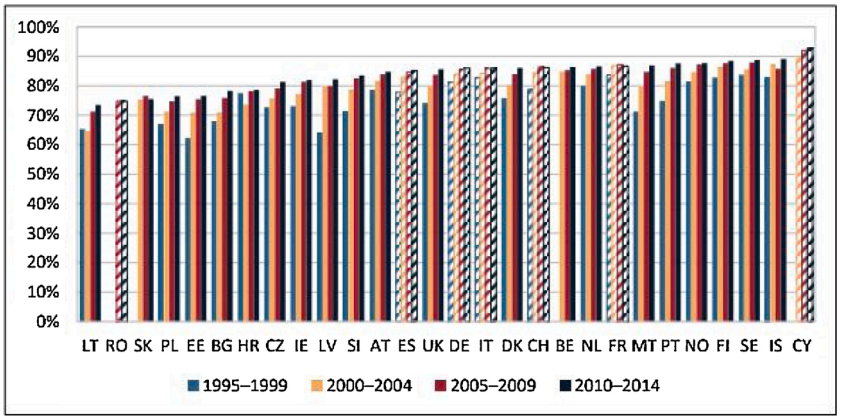

Fig. 5. 5-year age-standardized net survival rates for breast cancer in female European adult patients (15-99 years), 1995-2014. Hatched bars are based on regional data or neighbouring countries. Improvements are apparent, with well over half of countries reporting survivorship of over 80 % at five years, but with considerable diversity (from reference [6] with permission).

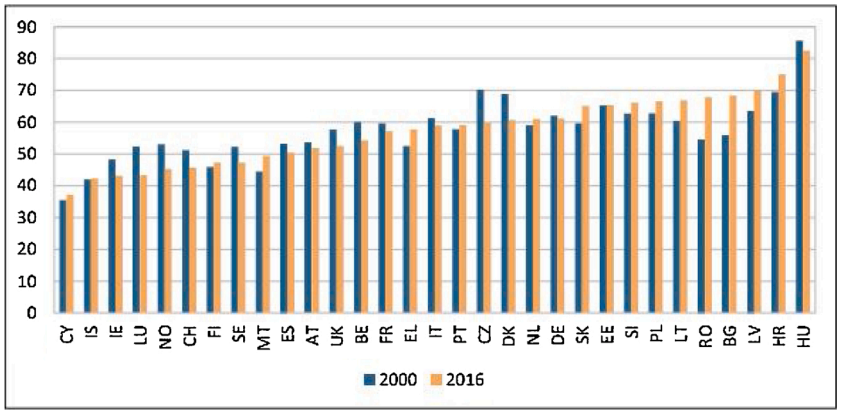

Fig. 6. Disability adjusted life years (DALYs) lost due to cancer per 1000 inhabitants in 31 European countries, 2000 & 2016 [6]. There is great diversity between countries. The biggest reductions in cancer related DALYs lost have been seen in Czechia, Luxembourg, Denmark and Norway; the biggest increases have been seen in Bulgaria and Romania. The cancers which cause the greatest disease burden measured in DALYs are lung cancer, CRC and breast cancer, with pancreatic and prostate cancer increasingly contributing to the cancer burden (from reference 6 with permission).

outcomes [105–109].

The Patient Advisory Committee of the European Cancer Organisation, established in 2008, provides a setting for 20 European patient organisations and bodies involved in patient care, to work together with ECO Member Societies and provide their direct insight into the challenges faced by cancer patients and inequalities in cancer care [51]. ESMO [50], in collaboration with the European Cancer Patient Coalition (ECPC) [52] produce ESMO Cancer Patient Guides. European cancer patient advocacy organisations and the Workgroup of European Cancer Patient Advocacy Networks (WECAN), co-produce a wide range of policy and strategy papers.

2. The European Code of Cancer Practice

The European Cancer Patient's Bill of Rights [1–4], which was awarded the 2018 European Health Award at Gastein [110] was the forerunner of the Code. The next step was to turn the concepts of the Bill of Rights into a Code and this was derived by a process of systematic

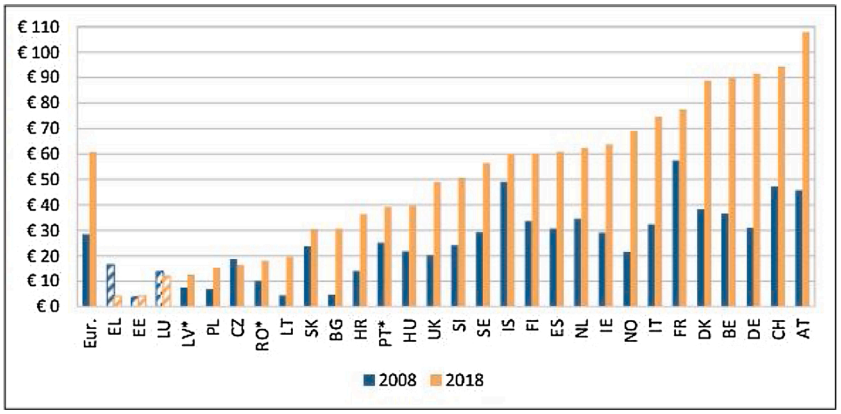

Fig. 7. Cost of cancer medicines per capita in 31 European countries at 2018 price levels and exchange rates, 2008 & 2018 (from reference [6] with permission). Hatched bars are based on regional data or neighbouring countries. There has been a substantial increase in most countries and considerable variation between countries. Highest expenditures are in Austria, Switzerland, Germany, Belgium and Denmark.

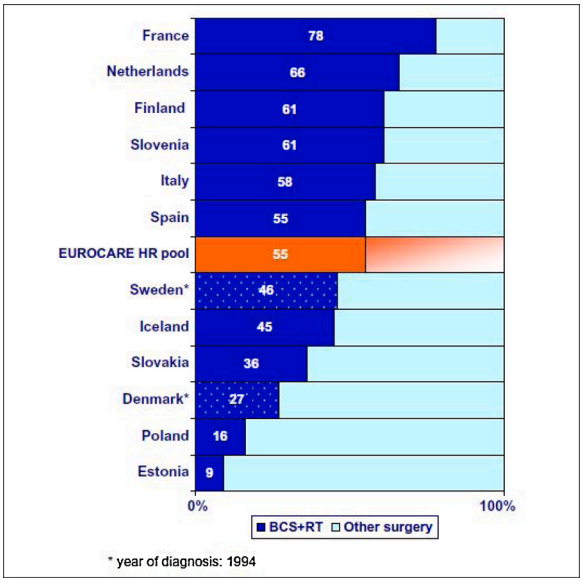

Fig. 8. The proportion of breast cancer (T1N0M0) patients receiving standard good clinical cancer practice with Breast Conserving Surgery and Radiotherapy in different European Countries. The results of a EUROCARE-3 study show the uptake of standard good clinical cancer practice in the surgery of women with localised, small, lymph node negative breast cancer ranged from 78 % to 9% [112].

co-production, with a core steering group - two patient advocates and two cancer professionals, reflecting our co-production values. They initially consulted with a group of 65 people with equal numbers of patient advocates and professionals [4]. The draft Code was refined by a smaller group of 14 patient advocates and professionals who formulated the patient Questions and drafted Explanations of each of the 10 rights captured in the Code. The whole programme was then reviewed by the member organisations of the European Cancer Organisation, the European Cancer Organisation Board and Patient Advisory Committee. The final version was checked for compatibility with existing systematically prepared guidelines and service specifications.

The ten rights in the Code are:

1) You have a right to equal access to affordable and optimal available cancer care, including the right to a second opinion.

Central to the European Code of Cancer Practice is the right of patients to access affordable and optimal available cancer care [1], (Fig. 1), (Appendix A). However, there is compelling evidence that not all countries, regions, hospitals and communities currently provide access to good clinical cancer practice, reflected in their less than optimal cancer patient survival [2–23,34–44]. The Comparator Report [6] gives net survival in a variety of cancers and countries. Figs. 4 and 5 show five-year age standardised net survival rates for colon cancer and breast cancer. There is clear evidence of improvement in survival for both, but with considerable variation in outcomes between countries.

The World Health Organization (WHO) has adopted a comprehensive measure of disease burden [6,111], Disability-Adjusted Life Years (DALYs). Fig. 6 shows the DALYs lost due to cancer in 31 European countries [6]. Studies are beginning to identify variations between European countries in the efficiency of cancer care. Increasing expenditure is usually associated with improvements in survival. However, in analysing the efficiency of cancer care delivery there is considerable variation between countries, which is not explained by expenditure alone [6, 45].

There is unequal deployment of cancer treatments across Europe [5, 6]. Fig. 7 shows expenditure per head of population on cancer medicines in 2008 and 2018 [6]. Fig. 8 shows that access to the best surgical care varies greatly in different European countries [34,55,112–115]. Considerable inequality exists in the utilisation of radiotherapy [36–38, 49,56,116,117], (Fig. 9). Monitoring variations in access to good quality care and its influence on outcomes, as is demonstrated by the work of the European Registry of Cancer Care, is a vital part of ensuring good practice for cancer patients [118].

2) You have a right to information about your own disease and treatment from your medical team and other reliable sources, including patient and professional organisations.

Excellence in patient-centred care requires informed decision-making following good communication and provision of good-quality information [5,9,119,120] (Fig. 3), (Appendix A). Communication

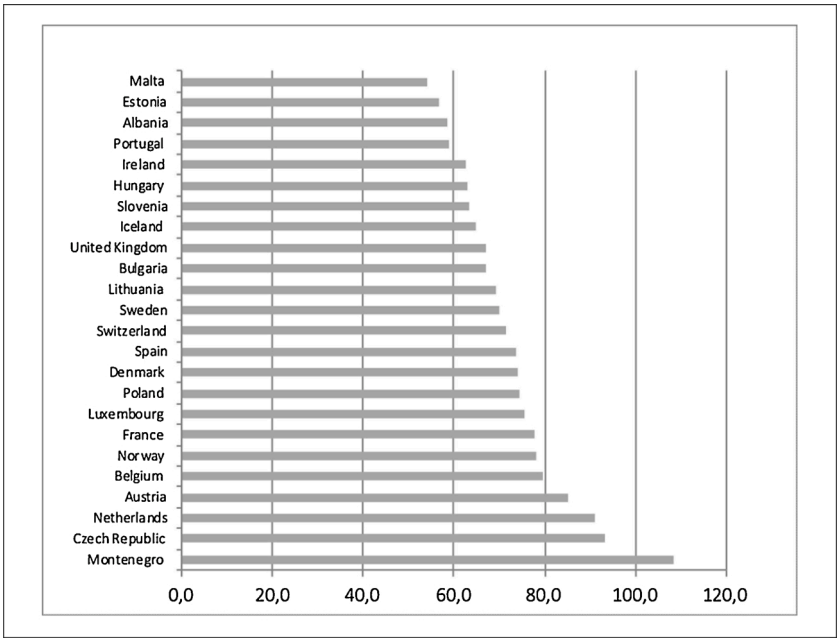

Fig. 9. Radiotherapy uptake in Europe. The figure shows actual radiotherapy utilisation as proportion of optimal evidence-based utilisation. In general, diversity is seen in the uptake of evidence based radiotherapy, the equipment available per citizen and per cancer patient, the optimal utilisation of radiotherapy treatments and considerable variation in radiotherapy staffing numbers [35].

Table 4
European Association of Cancer Leagues (ECL) advice to patients preparing for a consultation (adapted from reference [123].

1. **Before the consultation**: Ask a relative, friend, partner, carer or advocate to accompany you to your appointments, make a list of questions you would like an answer to, make a list of all medicines and pills you take, including vitamins and supplements, write down details of your symptoms, including when they started and what makes them better or worse, do not be afraid to ask your doctors to repeat and/or clarify anything they say, ask if you can record consultations on your smartphone.
2. **Before you leave:** Check you have asked all the questions on your list, know what the next steps are, ask who you can contact if you have any problems or further questions, ask for reliable sources of information about your disease and treatment options.
3. **After the consultation:** Keep all your notes safe - in case you ever need to refer to them, book dates for the next appointments in your diary, discuss the results of the consultation with your loved ones.

Table 5
The DREAM interview: key components and skills needed by cancer professionals conducting consultations (reproduced with permission from reference [119).

Data	Collecting accurate data, i.e. taking a clear medical history needs knowledge about appropriate use of open, focused-open and closed questions, and avoidance of leading and multiple questions Set up the interview carefully and allow adequate time; include a patient's spouse, partner or friend who will help their recall; ensure you know the patient's pre-existing knowledge – their 'starting point'
Relationship	Establishing a relationship or rapport, i.e. learning more about the patient's worries and concerns and making the patient feel comfortable by giving and asking information, not interrupting too much or looking at notes This needs awareness of verbal and non-verbal communication and the ability to engage in active listening
Empathy	Being empathic, i.e. responding appropriately to patient-led cues Acknowledge the burden of disease and treatment
Advice	Giving advice, i.e. explaining the logic and rationale for treatment, and putting complex information into layperson's terms This needs the ability to structure information into manageable chunks, to summarise and to constantly check understanding Encourage note taking or recordings: it is good practice to give patients brief notes of the main points at the end of the interview (these may be made by an accompanying healthcare professional)
Motivation	Providing motivation, i.e. ensuring that the patient understands the true therapeutic intent of treatment and feels motivated to embark on therapy with the likelihood of achieving realistic goals This needs use of unambiguous language and the ability to focus the patient on goals such as improving QOL

skills training including breaking bad news and explaining complex treatments and clinical trials, are now an important part of undergraduate education in healthcare and of continuing professional education in all oncology disciplines [121,122]. Good communication from healthcare professionals to patients and their families begins with a courteous introduction explaining who you are and what you are there to do, and that you will tell them the truth. Professionals should listen carefully to patients' history, problems and background. A good consultation will usually involve as much listening as talking. An organised approach to communication is helpful for both patients and professionals.

The Association of European Cancer Leagues (ECL) Patient Support Working Group [123] has produced a structured guide on how a patient may prepare for a medical consultation (Table 4). A well-structured example to aid cancer professionals to communicate well is the DREAM five-component protocol [119]. Table 5 uses the DREAM outline to summarise the features of an approach to good communication with cancer patients.

3) You have a right to information about the quality and safety of care, the level of expertise and the outcomes achieved for your type of cancer in the cancer care service where you are being treated.

Cancer patients and professionals need high-quality clinical data indicating the outcomes for patients undergoing care at cancer centres and hospitals at a national, regional and local level. Patients need the data to judge whether the service providing their own care is working effectively; healthcare professionals need the data to audit their results and determine how they can improve their practice; healthcare managers need the data to assess the value of the service they provide; policymakers need good data to underpin policy initiatives. Easy-to-use and interoperable IT systems and data managers are paramount [5,9,124]. These are not always found in hospitals or healthcare systems.

The provision of information to support cancer patients in their choice of centres is principally at a national level. A patient's individual service should be able to provide a point of access to this information. For example, the Italian Oncoguida [125] "*provides detailed, patient-oriented information on Italian hospitals and cancer centres providing cancer care, including volume of surgeries performed per tumour site, availability of psychological and physical rehabilitation services and contact details of patient associations involved at the hospital level.*" [125,126]. In the UK, "My NHS" website [127–129] can be accessed by a patient to examine the performance, staffing, clinical outcomes and treatment delivery of their cancer service.

4) You have a right to receive care from a specialised multidisciplinary team, ideally as part of a cancer care network.

Specialised multidisciplinary team (MDT) cancer care has been recommended by cancer organisations, governments, learned societies and patient advocacy organisations since the 1990s [71,130–133]. A key recommendation of CanCon is to *"Ensure equitable access to timely, high quality and multidisciplinary cancer care"*. However, it must be delivered efficiently and affordably, with the best possible impact and the optimal infrastructure and informatics [133], (Table 6). The evidence on the impact of MDTs is extensive but uneven. Kesson et al. [134] studied the impact of MDTs in Glasgow on breast cancer patient survival, finding improved survival and reduced variation in care. MDTs must be kept efficient to justify their cost. Human factors such as unequal participation, varying quality of leadership, inconsistent communication, and decision-making fatigue can all reduce the quality of the decisions [135–137]. The ERQCC [24–31] emphasises the varied impact of MDTs between different cancer types. Despite the importance of MDTs in all cancer types, the actual constitution of the MDT may vary among different cancer types. The OECI 27 quality standards for multidisciplinary teams are designed to reduce unhelpful inconsistencies in the way teams operate, to enable effectiveness of discussion and process, and to stimulate a culture of learning and continuous improvement in

Table 6
The impacts of Multidisciplinary Team (MDT) working (adapted from reference [133].

1. Treatment and care being considered by professionals with specialist knowledge and skills in the relevant aspects of that cancer type.
2. Patients being offered the opportunity to be entered into high-quality and relevant clinical trials.
3. Patients being assessed and offered the level of information and support that they need to cope with their condition.
4. Continuity of care, even when different aspects of care are delivered by different individuals or providers. The information provided by different team members must be consistent and clearly recorded, such that it can be readily transferred to other teams in hospitals or the community which may contribute to the patient's care.
5. Good communication among primary, secondary, and tertiary care.
6. Optimal data collection, for the benefit of the individual patient and for the purposes of audit and research.
7. Improved equality of outcomes as a result of better understanding and awareness of patients' characteristics and through reflective practice.
8. Adherence to national and local clinical guidelines.
9. Promotion of good working relationships between staff, thereby enhancing their job satisfaction, mental health and QoL.
10. Opportunities for education/professional development of team members (implicitly through the inclusion of junior team members and explicitly when meetings are used to devise and agree upon new protocols and ways of working).
11. Optimization of resources – effective MDT working should result in more efficient use of time, which should contribute to more efficient use of resources more generally.

Table 7
The CanCon definition of a Comprehensive Cancer Care Network (CCCN) (from reference [132] with permission).

A CCCN consists of multiple units belonging to different institutions dedicated to research, prevention, diagnosis, treatment, follow-up, supportive and palliative care, and rehabilitation for the benefit of cancer patients and cancer survivors.
These units interact and have a formal agreement to work together in a programmatic and structured way with common governance, in order to pursue their goals more effectively and efficiently through collective synergies.
Within the CCCN the care of patients is the responsibility of inter-professional teams that are multidisciplinary and tumour-specific. Each team or tumour management group works together for the benefit of patients with that particular type of tumour.
Within the CCCN all units work together and adopt uniform standards of care for cancer-specific pathways that are binding for the entire network.
The CCCN promotes a uniform system of quality assurance, and a unified informatics system for optimal exchange of information.
The objective of a CCCN is to provide comprehensive cancer care to all the people living in a certain geographic area, thus pursuing equality and the improvement of outcomes and quality.

The word unit is used to designate any component of a CCCN, whether an entire pre-existing institution or part of an institution. For example, a unit might be an entire cancer centre, an oncology department of a general hospital or a children's hospital, a mammography facility, a pathology laboratory carrying out mutation analysis, or a hospice [5].

the team [74].

Integrated Care within Cancer Networks is recommended by EPAAC and CanCon as a key requirement for optimal quality cancer care [5,7,71,86,132]. Specialised MDTs require a substantial team and infrastructure and a sufficient volume of activity to maintain high quality [77–85]. Integrated cancer care in Comprehensive Cancer Care Networks (CCCN, Table 7), can improve the quality of care and outcomes. Networks have a key role in delivery of care for people with rare cancers for whom they may often need to be extended internationally [138]. Cancer networks across Europe - for example those in France, Spain and the UK - have considerable differences in governance, management structures and degree of network maturity. [5,7,71,86–91]. Prades et al. [86] noted "*The cancer network model, epitomised by the UK experience, has shown great potential to improve health outcomes by making better use of scarce clinical expertise, enhancing service coordination, and increasing patient access to services and clinical trials*" [71,86–91]. This has recently been supported by Australasian findings [139,140]. There are currently no consistent frameworks for evaluating the effectiveness of cancer care networks, although OECI is in the course of piloting a specific set of network standards to ensure equity of access to high quality care for patients, wherever they live.

5) You have a right to participate in Shared Decision-Making with your healthcare team about all aspects of your treatment and care.

Decision-making in a clinical consultation may be passive in which the doctor takes the decision, active in which the patient receives information and then takes the final decision or there may be a shared or collaborative approach in which a doctor recommends a treatment taking account of the patient's views [119]. It must always be kept in mind that unwell and anxious patients may find it difficult to decide their treatment preferences. Shared decision-making is widely preferred but can be challenging, especially if a clinician or MDT have a strong view. A treatment preference may be right for the average patient but not right for an individual. Shared decision-making should result in less regret about the decisions taken. It should aid coping, resulting in better treatment compliance, which should improve QoL and survival. Cancer professionals require training and experience in communication to elicit truly educated/informed consent [119,141]. In a large US study [142], high levels of shared control were preferred by patients with more patient control observed in chemotherapy decisions and more physician control in surgery and radiation decisions. Ring et al. [143] found in women over 70 years with breast cancer that 58.5 % preferred shared decision-making. Wilding et al. [144] surveyed 17,193 men after prostate cancer treatment and found that regret about the treatment

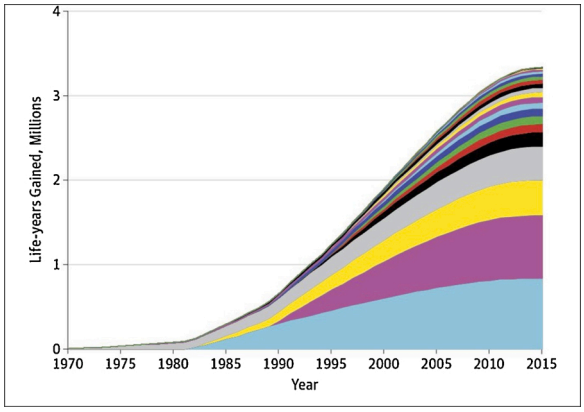

Fig. 10. Cumulative life-years gained through 2015 by SWOG clinical trials. The cumulative life years gained through the implementation of positive RCTs is plotted for each trial through to 2015. The colour coded areas represent cumulative life-years for each of the 23 studies evaluated. For each colour, the cumulative life years saved are plotted 1970–2015. The impact of each individual study is added with a new coloured segment so that the total cumulative, additive impact of all 23 studies combined is shown with the contribution of each study shown by a separate colour. Four studies are shown to contribute two thirds of the life years saved. Reproduced with permission [149].

decisions taken was more common when patients reported that their views had not been taken into account. Decisions may involve opinions from families, friends, and other patients and - increasingly in modern practice - internet sources.

Decision aid tools providing clear, comprehensible information in an appropriate format will help shared decision-making [119]. For example, the decisions faced by breast cancer patients include difficult options for the extent of surgery and modalities of adjuvant therapy [145]. An example of a decision aid tool is the PREDICT-UK online tool which helps patients and clinicians see how different systemic treatments for early breast cancer might improve survival after surgery [146].

A Cochrane Systematic Review was applied to studies which had sought to clarify the impact on patients of the treatment and screening options which were presented to them. The Review considered 55 clinical trials across the wide range of treatment and screening options. Its conclusion was that where patients had a greater participation in decision making, then they had greater comfort/satisfaction with the decisions taken [147].

6) You have a right to be informed about ongoing research relevant to you, and your ability and eligibility to participate in research.

To bring new cancer discoveries into clinical practice requires concerted basic research, research to translate the findings towards clinical use and clinical research. The transition from basic science and innovation to early phase clinical trials is often referred to as the "first translational gap". Second, an innovation whose concept is proved in early phase clinical trials, must be demonstrated in large scale late phase trials and then disseminated across a whole healthcare system, the "second translational gap" [148].

Research brings benefits to patients both through the implementation of its results and its influence on the quality of clinical cancer care. We have summarised those areas of research which are currently improving or likely to improve cancer practice in the foreseeable future in Table 3 [92–103]. While patients must be absolutely free to choose whether they wish to be individually involved or continue to be involved in research, it is essential that they have the right to be informed about research options and the research activities of their cancer care teams.

Clinical trials determine if a new treatment is better than or equivalent to existing treatments or diagnostic strategies. When trials are positive, then this should help improve patient outcomes. Even when new approaches are shown to be equivalent to existing approaches, this

can still result in better care, if the new approach is less toxic, less inconvenient or cheaper. The USA Southwest Oncology Group (SWOG) [149] in its 60-year history conducted 23 positive RCTs which established new standards for care. They estimated population life-years gained through 2015 by mapping the effect of the new treatments onto the US cancer population (Fig. 10). 3.34 million (95 % confidence limit, 2.39–4.15 million) life-years were gained at a cost of $125 per life-year gained, an impressive return on investment in lives saved for the money spent [149]. However, evidence from clinical trials may diffuse slowly into daily clinical practice. There may be a number of reasons for this, such as poor knowledge diffusion, insufficient resources, and inadequate reimbursement systems [37,38,150].

The claim that patients in clinical trials have better outcomes than patients with the same disease in the same institutions who are not in trials is not supported by systematic reviews [151]. However, a hospital which participates actively in research by entering patients into trials in large numbers, delivers better outcomes than a research-inactive hospital [152–157]. Research participation might stimulate the consideration of new evidence, introduce improved cancer treatments and equipment, while the interaction between researchers and clinicians can have an impact on all treated patients with the disease in that hospital. Systematic reviews support the positive influence of research participation on the processes of care delivery [152]. Clinical trial activity also correlates with improved care quality and patient satisfaction in hospitals [152–156]. Relatively small studies all highlight positive associations between research participation and patient survival (reviewed in 155). A large study in over 200,000 patients with colorectal cancer over 10 years in the English NHS showed that the provision of research infrastructure improved the recruitment, speed, quality and integration of clinical cancer research; in a multivariable case mix adjusted analysis there was a strong association between research participation and patient survival [157]. A review and literature meta-analysis supports the conclusion that research-intensive hospitals have substantially better outcomes, independently of their size, inferring a causal relationship [155].

7) You have a right to discuss with your healthcare team your priorities and preferences to achieve the best possible quality-of-life.

The increasing emphasis on QoL comes from greater awareness of the needs of patients and also from an increasing ability to measure those needs using Patient Reported Outcome Measures (PROMs). The first PROMs used in oncology were health-related quality of life questionnaires measuring physical symptoms, psychological distress, the impact on daily functioning and patient perceptions of their QoL and well-being [158,159]. PROMs such as the Distress Thermometer and the Hospital Anxiety and Depression Scale [160,161] were used as screening tools, included in oncology trials supporting patient-centred clinical conclusions. Digital data collection and electronic medical records allowed the collection of PROMs in daily oncology practice to screen for symptoms or psychological distress, monitoring symptoms and treatment response. PROMs can promote patient-centred care by highlighting concerns and prompting discussions; identifying psychological and physical problems; facilitating patient-doctor communication; engaging patients in shared decision-making; improving symptom control, patient well-being and patient satisfaction; improving patient survival and reducing care costs [158,162–171].

International organisations such as the International Society for Quality of Life Research (ISOQOL) and the Quality of Life Group of the EORTC have developed practical guidelines on how to incorporate PROMs in clinical practice [158,172,173]. The Patient-Centred Outcome Research Institute (PCORI) of the USA National Institutes of Health has published a “Users’ Guide to Integrating Patient-Reported Outcomes in Electronic Health Records” [174,175]. PROMs may be used to survey large populations to evaluate key healthcare outcomes such as the QoL of cancer survivors [176]. The international consortium SISAQOL (“Setting International Standards in Analyzing Patient-Reported Outcomes and Quality of Life Endpoints Data”) aims to improve the analysis and presentation of QoL data [177]. Guidance written by leaders of cancer patient advocacy organisations on how to include the patient voice in PROMs has been produced [178].

Table 8
Recommended model of professional psychological assessment and support (from reference [181].

Level	Who should provide it?	What should be assessed?	What is the intervention?
1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
2	Health and social care professionals with additional expertise (including CNS)	Screening for psychological distress	Use of standardised screening tools, e.g. the Distress Thermometer and the Hospital Anxiety and Depression Scale
3	Trained and accredited professionals	Assessments for pychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit therapeutic framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy

‘Psychological distress’ including worry, intrusive thoughts, low mood, poor concentration, sleep difficulties and appetite changes, below the threshold for a diagnosable psychiatric condition, are common in cancer patients. The prevalence of mental disorder has been shown to be between 30 % and 40 %, whereas major depressive illness is found in from 8% to ~25 % of people with cancer, and anxiety disorder in about 25 % [179]. These problems may not be detected consistently by oncology teams [180] and patients should be screened for psychological morbidity at key points in their disease trajectory [179,180]. Psychological support should be provided in a stepped-care approach which addresses the needs of patients with few psychological needs, through to those needing specific intervention [181], (Table 8).

The social impact of cancer may be considerable, not only at the time of diagnosis, when immediate readjustments may have to be made, but also possibly over many years following diagnosis. Early and late side effects of treatment result in chronic disability and restrictions in performing daily activities. Patients at all stages of disease report problems in all domains of life: in the home, with support services, aids and adaptations, with finances and insurance, employment including the self-employed, legal aspects with family affairs and wills, with relationships, sexuality and body image, recreation, holidays and with housing and transportation [182]. Although most patients are able to cope, a significant minority struggle. In 17,000 CRC patients, 15 % reported levels of social challenges which if found in clinical practice would have warranted some form of further assessment [176,182,183]. Patients with multiple social concerns or difficulties have been shown to be more likely to exhibit clinically significant anxiety or depression [182,184].

8) You have a right to receive optimal supportive and palliative care, as relevant, during any part of your cancer journey.

Evidence clearly supports the benefits of earlier referral to palliative care and this should be promoted more widely as an important step to counter the perception that referral represents oncological failure or imminent death. Developing more integrated clinical practices between oncology and palliative care is helpful [185–187]. Early palliative care improves symptoms, QoL, reduces acute hospital admissions, and may

improve survival [188–192]. Systematic reviews and pooled analyses of routinely collected data have demonstrated an association between early palliative care intervention and an increased proportion of home deaths as the preferred place of death. Integrating supportive and palliative care into oncology can result in less hospital admissions, reduction in stay in hospital, fewer intensive care hospital days, lower costs, and increased trial recruitment [187]. However, referring all patients to specialist palliative care at diagnosis with advanced disease is not currently feasible in most European cancer practices. Society's views on palliative care are another barrier, with misconceptions which include assumptions that palliative care is only for patients at the very end of life, and a lack of appreciation of the breadth of services provided [185–195]. However, some European organisations are setting a higher bar for earlier and more integrated intervention of specialist services, such as the ESMO-designated centres of oncology and palliative care, and the OECI quality standards, which define the optimal compositions of both palliative and supportive care teams, and structured referral processes [74,193].

9) You have a right to receive and discuss with your care team a clear, managed and achievable plan for your survivorship and rehabilitation.

The substantially increasing number of cancer survivors in Europe led the EU Joint Action on Cancer Control (CanCon) to focus on survivorship and rehabilitation as part of the *European guide on quality improvement in comprehensive cancer control* [5,196,197]. The EORTC and others have highlighted the importance of survivorship and addressing this need through research and innovation [63,198–201]. The European Cancer Organisation has established a Survivorship and Focussed Topic Network [51]. CanCon used the very inclusive definition of survivorship provided by the US National Coalition for Cancer Survivorship [202]: 'the *experience of living with, through and beyond a diagnosis of cancer*'. The definition of a survivorship plan by the US National Cancer Institute is: '*A detailed plan for a patient's follow-up care after treatment for a disease ends"* [203]. In preparing the Code, we have focused on the period of time after some active cancer treatment has been successfully finished. All divisions are quite artificial and an awareness of survivorship-related issues should be maintained at all parts of a patient's journey [184–204].

In Europe during the last six years, there has been increased awareness of survivorship challenges faced by cancer patients leading to policy makers adapting the law related to financial challenges. Innovative measures have been taken in France, Belgium, Luxembourg and the Netherlands establishing a "Right to be Forgotten" such that cancer patients do not face discrimination [200,201,204–206]. This may allow some cancer survivors to apply for insurance without having to disclose their history of cancer. Even when insurers know about a person's cancer diagnosis - for example, based on a person's previous insurance claims - they are not allowed to incorporate this information into new insurance policies. However, there is a need to provide equal access for all Europe's cancer survivors to such legislation. Recently, the EU Commission has also stressed the need for a "Right to be Forgotten" [14,15].

CanCon identified the importance of a **survivorship care plan** for the follow-up of cancer survivors to overcome the many factors impeding good QoL [196,197], covering both medical and non-medical aspects of care. Models reported include the shared care model and the availability of specialised survivorship clinics. Evidence suggests that there is considerable added-value for patients and healthcare systems with the use of survivorship care plans, even though they are currently far from routinely employed [207–209]. However, for their accredited cancer centres, an OECI quality standard specifically requires that a personal survivorship care plan is discussed and agreed with each patient, covering all their requirements and available support mechanisms [74]. Self-management support can help patients to manage the issues they face as cancer survivors, as active partners, working in collaboration with healthcare providers. The main messages on survivorship from CanCon are shown in Table 9 [196,197].

Table 9
The main messages on cancer survivorship from the CanCon Member State Joint Action Against Cancer (from reference [5].

Cancer survivors' follow-up, late effects management and tertiary prevention needs should be anticipated, personalized and implemented into care pathways, with active participation of survivors and relatives
Improvement is needed in early detection of patients' needs, and their access to rehabilitation, psychosocial and palliative care services is required
An integrated and multi-professional care approach is required with coordination of community care providers and services to implement a survivorship care plan that enhances patient self-management and QOL
For child, adolescent and young adults survivors, late health and psychosocial effects of cancer and its treatments should be anticipated and addressed
More research in the area of survivorship is needed to provide data on late effects, as well as the impact and cost-effectiveness of supportive care, rehabilitation, palliative and psychosocial care interventions

Table 10
The challenges of cancer patients Returning to Work (RTW) (from reference [215].

1. The total economic loss to the European Union (EU) due to lost working days to cancer was estimated to be EUR 9.5 billion in 2009, not all related to unsuccessful RTW.
2. When returning to work, survivors may face difficulties in balancing work and treatment demands, including negative attitudes or behaviours among their colleagues and employers.
3. Small or medium sized companies (< 250 workers), especially smaller ones, and the self-employed lack resources for RTW strategies or programmes, and support for them is needed.
4. Results from the modest scientific literature show that only multidisciplinary interventions that combine vocational counselling with patient counselling and physical training have increased RTW rates, although only to a small extent.
5. Workplace accommodations are needed to provide more flexibility or a reduction in working time, including paid leave for healthcare appointments, adjustments to workload and duties, and the provision of assistance.
6. Psycho-educational interventions, such as advising cancer survivors by telephone or providing information on a dedicated website are needed.
7. A range of RTW instruments, practices, policies and interventions exist for workers with cancer, and these are considered essential for improving the work outcomes of those diagnosed with cancer.

An increasing proportion of survivors are concerned about fertility issues [210–213]. Consideration of early referral to a fertility specialist should be incorporated into the MDT strategy. Prevalence rates of sexual difficulties associated with cancer and its treatment vary widely, depending on the diagnosis and treatment. Discussing the sexual consequences of cancer is difficult for healthcare professionals and patients alike. Screening patients and the use of PROMs may assist busy clinicians. Sexual difficulties may improve over time with medical, psychological and relationship strategies [214].

10) You have a right to be fully reintegrated into society and protected from cancer-related stigma and discrimination, so that, in so far as is possible, you can return to work and a normal life.

The physical, social and psychological challenges faced by cancer survivors have been summarised in Rights 7, 8 and 9. However, a critically important aspect of reintegrating into normal life for many cancer patients involves returning to work. The European Agency for Safety and Health at Work (EASHW) in 2018 reported on "Rehabilitation and return to work after cancer - instruments and practice" [215] and evaluated good practice, case studies, qualitative research, and stakeholder views. They found that some patients had diminished work productivity and ability early in treatment as expected, but these consequences can also last years after diagnosis (Table 10).

The Association of European Cancer Leagues [54] has identified the issues and potential solutions to the challenges faced by cancer patients at return to work [54,216]. Among all chronic conditions, cancer has by far the highest prevalence of work loss and reduction in work functioning, with an average return to work rate of 64 % after 18 months,

Table 11
Advice to employers from the Association of European Cancer Leagues (ECL) (from reference [216].

Simple solutions can make big difference, such as: • Flexible and reduced working hours • Working from home • Additional work breaks • Time off for medical appointments • Sick and compassionate leave • Suspension of working alone • Alternative employment (change of post) • Reallocation and prioritisation of work duties	• Temporary change of work area • Training for new skills • More convenient parking space • Mentoring colleagues and choosing a cancer issues supervisor • Avoiding excessive travel

and a greatly increased risk of unemployment [183,215]. Employers face a communication challenge with employees diagnosed with cancer and often do not understand the needs of the patient to return to work. Employees may feel guilty about time off work and be nervous about job security and promotion. They may fear an uncertain future, be embarrassed with colleagues, lack personal confidence to work efficiently and have financial concerns connected to their diagnosis and treatment.

ECL (Table 11), [54,216] urges employers:

1 Do not postpone problems associated with returning to work and deal with them as soon as possible.
2 Support a good and fluid communication during the whole pathway.
3 Be flexible on working conditions where possible.

These solutions are aimed at advising employers and employees but they can provide a useful framework for planning for self-employed patients and their families, who will face considerable, work-related challenges.

3. Discussion and next steps

The European Code of Cancer Practice [1] provides a tool to help patients navigate the significant challenges they face when diagnosed with cancer, as well as providing cancer professionals with help in the development of their own patient-centred approaches to good cancer practice. The Code represents an invaluable aid to training patient advocates, professionals and trainees in all professions, based on the best available medical literature and evidence.

In order to achieve the goals of improved cancer outcomes and QoL, an active programme of dissemination, implementation and evaluation of the Code is needed. We envisage the Code as a core resource to be retained and updated. However, to be fully effective it will have to be relevant to all countries and regions in Europe, to patients with many different cancer diagnoses and to all age groups. This will require its adjustment to be meaningful and accessible for such a wide range of audiences. Careful critical evaluation of the Code's uptake, impact and content will be needed at a European level and also in individual countries, regions, hospitals and communities. Evaluation findings should be shared and fed back to influence the Code and its developments [217]. Currently, the Code has been translated into 25 languages, facilitating its dissemination and deployment across Europe. The EU Health and Food Safety Commissioner has indicated her support for the wide dissemination of the Code.

The provision of evidenced-based guidance in a format that is accessible to patients and professionals can directly influence individual consultations and help in the more consistent introduction of good practice and improve outcomes. The prestigious award given to the programme [98] and the recent support and formal endorsement of the current EU Health Commissioner and her colleagues add to the Code's credibility [1]. However, we envisage that the use of the Code will improve practice and outcomes through a process of iteration between informed patients asking evidence-based questions and the clinicians and policymakers who are thereby consistently challenged to improve their own practice and policies and to influence their colleagues and trainees [218]. The Code should also influence the further development of quality standards and service specifications in hospitals and other settings.

Declaration of Competing Interest

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Appendix A

THE EUROPEAN CODE OF CANCER PRACTICE: Explanations of the Rights of the European Code of Cancer Practice

1) EQUAL ACCESS

You have a right to:

Equal access to affordable and optimal available cancer care, including the right to a second opinion.

Explanation

European cancer patients should receive affordable, best available cancer care in their own country which is comparable to other high quality cancer services in Europe. The cornerstone of the European Code of Cancer Practice (ECCP) is the right of Europe's cancer patients to have equal access to such cancer care. This means that you have the choice where to be treated and by whom, coupled with the right to obtain information about where best results are achieved. If you have a rare cancer (or are a paediatric patient), you also have the right to engage with the European Reference Networks (ERNs) relevant to your disease,

if good clinical cancer practice for your disease is not available to you within your local area. Each cancer patient, with their family and carers, should have the opportunity to discuss with their healthcare professionals whether the care that they will receive is the best available within their healthcare system and whether it is of the standard of good clinical cancer practice required by clinical guidelines.

Currently, there are inequalities in access to best available cancer care, both within and between European countries and between different regions and communities within some countries. Many factors determine these inequalities, including the cost of care, the organisation of care, access to the right technologies, and the availability of skilled healthcare professionals to deliver the required treatment to the highest standard. In many countries, it is possible to access good clinical cancer practice which is in keeping with published guidelines based on the best available scientific and biomedical evidence. This may be provided close to a patient's home or, when essential, by referral to a cancer centre which may be some distance away. Discussions between the patient and cancer professionals should identify the best available care options, so that the patient can make an informed choice.

Patients should always have the right to a second opinion, in relation to their diagnosis and/or the treatment of their cancer and subsequent care.

2) INFORMATION

You have a right to:

Information about your own disease and treatment from your medical team and other reliable sources, including patient and professional organisations.

Explanation

European cancer patients are entitled to reliable, good quality, comprehensive information from their hospital about their disease, its treatment and the consequences of that treatment. Patients should be informed that they can ask questions about the diagnosis, treatment and the consequences of the disease and/or its treatment, as well as receiving information on nutrition, physical activity, psychological aspects, etc. The hospital should also refer the patient to patient organisations which can provide invaluable information and support at many levels. In some countries, patient organisations and hospitals organise information sessions for newly diagnosed patients, so that all their questions can be answered and ideas exchanged.

Although patients are entitled to all relevant and comprehensive information if they so wish, how much information a patient wants about their cancer is up to that individual. Some patients prefer to be given a relatively small amount of basic information, leaving the complexities to their healthcare professionals. However, increasingly most patients want to have a clear picture of their illness, how it can be treated and to receive sufficient information to be able to make informed decisions about their care and be reassured that the treatment they will receive will be the best available for them.

Healthcare professionals will, in good modern clinical practice, explain to patients the nature of their illness, its extent and how that is measured, and the options for treatment and their likely outcomes. Explanations may come from the doctors or other members of the healthcare team. Cancer nurses will often have special communication skills and actively contribute to the consultation, either jointly with other healthcare professionals or individually and separately with the patients as required. The patient has the right to have someone of their choice with them during consultations and communications, often a close family member or friend. They have the right to ask for information to be repeated in a meeting or in subsequent meetings and presented to them in language that is accessible and clear. Consultations may be recorded if a patient so wishes and with the consent of others present at the time, and the recordings used by the patient as a record and reminder of what was said. During the COVID-19 pandemic, many consultations have been performed online, to help ensure the safety of the cancer patient. Online advice on how to prepare for such consultations is available. It is important to ensure that patients are comfortable with this approach and that these consultations mirror, in as much as is possible, the face-to-face consultation. Patients should have the right to choose which type of consultation best suits their needs and situation.

Information given at a consultation should be supported with good quality, relevant and clearly-written material provided by healthcare professionals, with appropriate explanations for the individual patient. Valuable written material is also available from patient advocacy organisations in many European countries. Guiding patients to reliable online material for subsequent reading is also important. Patients will often access information themselves online. Healthcare professionals should be prepared to answer questions about online findings and in particular relate this information to the patient's individual cancer journey. Some websites will be highly evidence-based, while others will be more speculative. Engagement with healthcare professionals and patient advocacy organisations should help patients and their carers to successfully navigate online cancer advice.

3) QUALITY OF CARE, EXPERTISE & BEST OUTCOMES

You have a right to:

Information about the quality and safety of care, the level of expertise and the outcomes achieved for your type of cancer in the cancer care service where you are being treated.

Explanation

European cancer patients should be given access to information about the care provided and the outcomes achieved by their specific cancer healthcare team. This is essential to allow patients to take informed decisions about their treatment and where it is delivered.

Different healthcare professionals deliver specific aspects of a patient's diagnosis and care. While primary care and general practice healthcare professionals have skills that can help in identifying suspicious symptoms, referring patients for a cancer diagnosis and supporting the individual through their healthcare journey, they will not have specialised cancer treatment expertise. Specialised cancer care should be given by a team of healthcare professionals with expertise in a specific cancer and its treatment in a hospital or a dedicated cancer centre. Patients have the right to know the level of expertise and experience of healthcare professionals and teams who will be looking after them. Therefore, they need access to information about the results their healthcare team have achieved, for their specific cancer, and how it compares to expected results from other hospitals or cancer centres.

In order to achieve the best results for patients, their specialist care team must have substantial experience across a broad range of professional competencies. They must be well led and coordinated, have adequate resourcing and participate in training programmes to maintain and upgrade their skills. Professional organisations across Europe recommend the required level of activity and competency which is appropriate for a team (eg number of patients with that particular cancer type cared for by the team per year), to ensure the best results for patients. Application of the available European Cancer Organisation's Essential Requirements for Quality Cancer Care can help support the delivery of best available care.

Care teams should regularly audit their results and compare them to other similar teams in other institutions. However, comparisons between teams and their outcome results is not always straightforward, as different teams may be dealing with patients at different stages of their cancer and be using different treatments. Nonetheless, informative, careful comparisons are possible and this process ensures that the care team is continuously looking to improve and achieve the best outcomes for patients across all indicators of the quality of the care provided. This information should be made publicly available and accessible to patients to consider when they are making their decisions on treatment options and should be published by healthcare institutions, government departments and/or professional organisations.

4) SPECIALISED MULTIDISCIPLINARY CARE

You have a right to:

Receive care from a specialised multidisciplinary team, ideally as part of a cancer care network.

Explanation

European cancer patients' care should be organised so that the best decisions about choices of treatment are made, ensuring best available care is delivered in the most effective and timely way, as close to the patient's home as is safely possible (link to the Health Systems and Treatment Optimisation Network). The two organisational structures recommended, the specialised multidisciplinary team (MDT) and the cancer network, are both well supported by evidence and experience.

Specialised Multidisciplinary Team (MDT)

A specialised MDT comprises all of the different healthcare professionals, whose combined knowledge ensures that the best treatment options are discussed with the patient and that Shared Decision-Making (SDM) takes place. All treatment options should be considered and can be advocated by the relevant specialists; all relevant doctors, nurses and other cancer care professionals should be informed and kept up-to-date through all stages of the patient's journey.

Patients should be made aware of the MDT, its purpose, membership, when it meets, and that their case is being/has been discussed. They should receive the outcome of these discussions within a locally-agreed timeframe. A patient's views, preferences and holistic needs should be presented to the MDT by a member of the team who has met the patient and discussed these aspects with her/him. Patients should be informed, in a consultation with the appropriate MDT member, of the results of MDT discussions, and its recommendations and the preferred options for treatment. Patients should receive information, consistent with their wishes, about their cancer, their diagnosis, and their treatment options, including therapies that may be available by referral to other MDTs in other cancer networks, ensuring a well-informed choice is made about their individual treatment and care.

Cancer Networks

It may not be possible to have all of the members of every MDT in every location where a cancer patient is diagnosed or treated. It may be necessary to centralise care by moving a diagnosed patient to a specialised centre. This might happen, for example, if the patient has a rare/very rare cancer and there is no expertise for treatment of this cancer in the patient's closest institution. To ensure that care is integrated in a well-organised and streamlined way, the "Cancer Network" or the "Comprehensive Cancer Care Network" model has been developed. This involves different parts of the healthcare system including primary care, smaller community hospitals and large cancer centres working together, communicating effectively and ensuring that the patient's travel to the specialised cancer centre is kept to the necessary minimum. In this approach, certain aspects of treatment are delivered in the specialised centre, while other aspects are safely provided closer to the patient's home. Cancer care plans and long term survivorship plans should be shared between all parts of the network and regularly updated.

5) SHARED DECISION-MAKING

You have a right to:

Participate in Shared Decision-Making with your healthcare team about all aspects of your treatment and care.

Explanation

European cancer patients should have a choice as to how decisions are taken about their cancer care and that choice should include Shared Decision-Making (SDM). Patients will have individual views about what is important in their life at the time of diagnosis and how they wish decisions to be made. While some patients may prefer for the doctor to take the decisions; most will prefer to take the decisions themselves. However, increasingly in good modern clinical cancer practice, a shared or collaborative approach is being employed, in which a doctor recommends treatment but takes account of the patient's situation and views after careful discussion.

SDM allows patients to fully inform themselves before making any choices about their treatment. Patients should have the possibility (either through the hospital or a patient advocacy organisation) to discuss with other patients who have gone through the same treatment successfully, to better understand the consequences of the treatment and how it will affect their quality-of-life. SDM also entails understanding the context in which the patient lives and identifying variations in the treatment plan, based on the patient's specific situation. A fully informed patient can also have the option to not (or to no longer) receive specific anti-cancer treatment such as surgery, radiotherapy or chemotherapy.

SDM requires good communications between the patient, the patient's carers and family and the healthcare cancer professionals. The approach has to be tailored carefully to fit the needs and preferences of individual patients, whose views for the level of input into decisions will vary. The family/social/cultural situation may also impact on the individual patient's care and should be considered. There is no single "best approach". Communicating choices about treatment must begin by clarifying the patient's knowledge about cancer and its treatment and how much involvement in decision-making the patient wants, both at diagnosis and throughout their journey. It is also helpful to clarify what the patient considers to be a 'good' outcome from treatment. Family involvement is often helpful, although the views of family members may be different from the patient's perspective.

There is good evidence that clinical decisions should be informed by a consultation between the healthcare professional and the patient that involves clarification of the patient's wishes and preferences, clear information about the purpose of treatment and the benefits/risks of the treatment. Patients want a good doctor-patient relationship: a doctor who is approachable, understanding and provides respectful care. Information needs to be uncomplicated, specific, in lay language and as unambiguous as possible. Communication which strongly directs a patient to a single option can have negative consequences. Evidence suggests that appropriately-judged SDM will improve patient outcomes and wellbeing and reduce the risk that patients will subsequently regret the decisions that have been taken.

SDM is a key component of patient involvement and engagement, in which healthcare professionals encourage patients to influence how their own care and healthcare services are delivered. This relates to the wider concept of patient empowerment, in which patients may undertake self-driven initiatives to influence how healthcare services can be improved.

6) RESEARCH & INNOVATION

You have a right to:

Be informed about ongoing research relevant to you, and your ability and eligibility to participate in research.

Explanation

European cancer patients should be informed about any ongoing research and innovation in the cancer service which is providing their care, while recognising that most patients will receive standard-of-care treatment. Research and innovation have underpinned improvements in outcomes for cancer patients in recent decades, with long-term survival increasing to over 50 % of cancer patients in many European countries. Further improvements will depend substantially on appropriate implementation of research and innovation discoveries. If relevant clinical trials are available in another hospital which are not being offered in the patient's hospital, patients should have the option to change hospital in order to participate. Patients should have the right to participate (or refuse to participate) in clinical research. The informed decision that they take, after careful discussion with the clinical investigators, is a personal one. Patients must also be assured by the clinical team that a decision to not participate in clinical research or to withdraw from a research study, will not adversely affect their care.

Clinical cancer research provides the evidence which ensures patients receive the best available care. It improves healthcare delivery, leading to better outcomes and improved quality-of-life for patients. Research which links the laboratory to the clinic is an essential component of a comprehensive cancer control strategy. There is evidence that research-active hospitals provide better care, achieve higher levels of patient satisfaction and deliver improved survival for patients compared to hospitals that are not active in research.

There are many kinds of clinical research. In some, researchers will ask for a patient's consent just to collect information about them for research purposes. In other research, the patient's diagnostic tests and treatments may be directly determined by clinical research protocols, but only after the patient has been fully informed and has given their consent. Patients may be asked to consider whether they are prepared to receive a new experimental treatment, in addition to or after they have received the standard care. They may also be invited to join in a randomised controlled trial (RCT). Here, one group of patients receive the standard-of-care treatment, while a second group of patients are allocated to a different treatment that is under trial. The process of allocation to the groups is called randomisation and it ensures that the two groups are truly comparable so that the results achieved are robust. At the end of the trial, results for the two groups of patients are compared so that the better treatment can be identified with confidence and used in future to improve cancer care.

Clinical research is highly regulated and carefully monitored to ensure that it is properly conducted, and that patient participation is properly sought with written informed consent and appropriate patient information. Very importantly, it is strictly monitored to ensure the maximum possible safety for patients who choose to participate in research studies.

7) QUALITY-OF- LIFE

You have a right to:

Discuss with your healthcare team your priorities and preferences to achieve the best possible quality-of-life.

Explanation

European cancer patients should expect to live as normally as possible with the optimum quality-of-life following their diagnosis, during treatment and through survivorship. Patients must be thoroughly informed on both medical and non-medical aspects of care and survivorship. Patients and their healthcare professionals must work together to preserve quality-of-life, while maximising chances of survival or cure. This will mean a focus not only on the patient's survival, their physical symptoms, test findings, the technological aspects of their care and the side-effects of treatment, but also the impact on daily functioning and wellbeing, relationship problems, work-related issues, financial hardship and social isolation. This may be particularly important and challenging when cancer treatments are associated with significant toxicity in the short, medium or long term. Striking the right balance in terms of survival and quality-of-life is particularly challenging where this risk of toxicity is associated with treatments that deliver only modest or uncertain improvements in the person's survival. Maximising the quality of patient's lives is now considered a hallmark of successful cancer care. Referring patients to patient advocacy groups will provide additional support, particularly on the issues that patients specifically find challenging.

Methods for measuring quality-of-life are now increasingly used in cancer care and clinical research, in particular Patient Reported Outcome Measures (PROMs). PROMs are defined as 'any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.' PROMs provide a formal measurement of the patient's experience of symptoms, treatment, daily functioning and health-related quality-of-life (HRQOL), and they reveal important patient-focussed information on quality of care. PROMs can be measured using carefully developed and validated questionnaires (sometimes called "tools" or "instruments") in clinical practice and in clinical trials. PROMs are developed jointly by patients and professionals and include questions derived from patients' concerns and experience.

Psychological distress is commonly experienced by cancer patients during their treatment and thereafter and is a major factor in poor quality-of-life, reflected in challenges such as self-esteem, changing roles of couples in relationships, social isolation etc. In a minority of patients, it may even precipitate a psychiatric disorder such as clinical depression. Healthcare services should provide psychological support, both to detect and manage such changes in the person's wellbeing. During and after their treatment, many cancer patients may experience social difficulties in all domains of life in their homes, in their interaction with healthcare services, with personal finance, with family relationships and in housing and mobility. Cancer patients should expect that healthcare professionals and healthcare services are aware of these challenges and are able to advise on and mobilise the appropriate assessments and measurements, advice and support to reduce social and financial difficulties.

8) INTEGRATED SUPPORTIVE & PALLIATIVE CARE

You have a right to:

Receive optimal supportive and palliative care, as relevant, during any part of your cancer journey.

Explanation

European cancer patients should have access to supportive and palliative care at any point of their cancer journey, from diagnosis, as survivors or in end-of-life care. Most cancer patients require supportive and palliative care at some stage of their care pathway. This may be particularly true of patients whose disease will prove ultimately not to be curable, but is also relevant for many patients who, sometimes following complex and difficult treatment programmes, achieve long term survival and good quality-of-life. As a patient, you have the right not to receive specific anti-cancer treatment such as surgery, radiotherapy or chemotherapy, but to choose supportive and palliative care to alleviate your symptoms. You have the right to make your own end-of-life decisions and for your choices to be respected as far as they can be within the current laws of the country within which you are receiving your care. You may choose to make decisions about your care in advance of the immediate need for them so that your wishes are clear for the future.

Supportive and palliative care can be provided from many sources within healthcare, in the community, in hospitals or hospices, from patients' families and carers and from patient organisations. It may be provided by the cancer care team and by full-time palliative care professionals. Expert supportive care is often to be found in specialised palliative care units, where skills in the patient's psychosocial support and symptom relief complement the complex often highly technical treatment options that are tailored to maximise quality-of-life.

There is evidence that involving supportive and palliative care early in the management of patients with cancer can improve their quality-of-life and in some circumstances improve their survival. Providing patients with good communication and supportive and palliative care may improve wellbeing and outcomes, reduce hospital admissions and length of stay and lower overall healthcare costs.

In most European countries, palliative care is a separate clinical discipline from oncology and the teams providing palliative care are responsible for many patients, not only those with cancer. However, the support of cancer patients is a large part of palliative care and the multidisciplinary palliative care teams have substantial expertise in the support of cancer patients and the management of their symptoms at all stages of their cancer pathway. Close working between cancer care and palliative care teams is a feature of good clinical cancer practice.

9) SURVIVORSHIP & REHABILITATION

You have a right to:

Receive and discuss with your care team a clear, managed and achievable plan for your survivorship and rehabilitation.

Explanation

European cancer patients' care should be supported in their needs as a cancer survivor. In response to the growing number of people surviving cancer in Europe, there has been increasing focus on the quality of survival. In this setting, "survivorship" has various definitions. It can include anyone diagnosed with cancer and include their entire cancer journey. More often, the focus will be on patients' survival from the period of time after they complete their active treatment. However, preparations to support survivorship can begin before active treatment is completed. A number of patient advocacy organisations have extensive experience in this area and patients should be referred to these

organisations for information on support groups and guidelines, including on work- and finance-related issues.

Cancer and its treatment can have a considerable and long-term impact on everyday life. Some cancer survivors may face a range of challenges including physical problems, poorer quality-of-life, psychological distress, sexual problems, problems with social relationships and financial concerns. Some consequences may emerge five or ten years after treatment (late effects) and can have a significant impact. For example, cancer patients may be at greater risk of a second cancer; some chemotherapy can increase the risk of heart disease, and long-term hormone therapy can sometimes be related to development of osteoporosis.

Supporting cancer survivors includes providing psychosocial aspects of support, such as coping with disruption to one's life, managing the consequences of treatment, living with uncertainty and lifestyle changes. Being a cancer survivor may disrupt one's social and sexual roles and identity. Patient advocacy organisations can offer significant help to support the cancer survivor.

High-quality cancer care should include an active approach to the challenges that patients face as cancer survivors. Every patient should be given a **survivorship cancer plan,** prepared for them in consultation with their cancer care professionals and fully explained. Patient advocacy organisations have a lot of experience in the practical issues that arise (eg relating to work, travel, leisure activities etc) and should be consulted. It is important that the cancer professionals and patients together identify and discuss any particular risks that the individual may have; specific approaches can then be taken to reduce those risks. These may include lifestyle changes such as giving up smoking, maintaining exercise, ensuring good nutrition and a healthy body weight. They may also involve medical follow-up measures including screening for the late complications of cancer and its treatment. Supportive care should be available for those patients who experience psychological distress, sexual or social problems as well as for those who have physical problems or late complications of the treatment or the disease. Survivorship care plans should be regularly reviewed and updated to reflect changes in circumstances and evolving life goals.

10) REINTEGRATION

You have a right to:

Be fully reintegrated into society and protected from cancer-related stigma and discrimination, so that, in so far as is possible, you can return to work and a normal life.

Explanation

European cancer patients should be able to reintegrate into society to the fullest extent possible, regardless of many factors including age, place of residence, sexual preference, gender, ethnicity, cognitive ability, religion, psychological state, education and job, and socio-economic class. However, increasing numbers of cancer survivors are facing challenges in some or all of these areas as they reintegrate into society. Work-associated stigma may include loss of employment, lack of opportunities for promotion or international work-related travel. Survivors should be able to obtain appropriate support and advice to help them with the process of reintegration, to sustain their quality-of-life, to ensure their ability to earn a living and to have an active and fulfilling social life and to contribute to society. These supports and advice should be signposted at the earliest possible stage by the cancer care team; some may be delivered by the cancer care teams themselves while others may be provided through patient advocacy groups (who will have specific expertise in advising survivors on social legislation, talking to employers, etc), community groups and government agencies or employers.

The diagnosis of cancer may disrupt family and social life and may lead to substantial absence from work through sickness. Cancer survivors may have long-term symptoms as a consequence of their disease or its treatment. Fatigue, emotional and mental health problems, persistent symptoms or reduced attention and memory can significantly diminish a cancer survivor's working abilities, usually in the short term but occasionally in the longer term. There is an increased risk of unemployment among cancer survivors, perhaps 1.4 times higher than the general population of similar age.

Interventions that can help with reintegration into the workplace and other aspects of life can include workplace arrangements to allow flexible working or reduced working hours, modifications of duties or the provision of assistance in a working role, and psychological and educational interventions. These may sometimes be provided by telephone or websites or through patient advocacy groups specialising in this type of support. Employers, however well motivated, may need some help to design interventions that support cancer patients in returning to the workplace. Healthcare teams and some patient advocacy organisations can help to guide back-to–work strategies, including making agreements with the employer at the time of diagnosis and discussion with Human Resource departments on return to work. Some countries offer flexible reintegration schemes through social services. At the moment, provision of support for cancer patients returning to the workplace varies substantially across Europe. Cancer patients should also have the Right to be Forgotten, so that a previous diagnosis and treatment does not stigmatise cancer survivors in any way on their journey to return to normal living.

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